Pregnancy Loss/Still Birth/Neonatal Death (PLSND) Questionnaire

Event Category:	Trigger-Based
Event:	Child Loss
Administration:	PV1, PV2, Birth
Instrument Target:	Child
Instrument Respondent:	Pregnant Woman; Biological Mother
Domain:	Questionnaire
Document Category:	Questionnaire
Method:	Data Collector Administered
Mode (for this instrument*):	Phone, CAI
OMB Approved Modes:	In-Person, CAI; Phone, CAI; Web-Based, CAI
Estimated Administration Time:	6 minutes
Multiple Child/Sibling Consideration:	Per Child
Special Considerations:	N/A
Version:	1.0
MDES Release:	4.0

*This instrument is OMB-approved for multi-mode administration but this version of the instrument is designed for administration in this/these mode(s) only.

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GENERAL PROGRAMMER INSTRUCTIONS:

WHEN PROGRAMMING INSTRUMENTS, VALIDATE FIELD LENGTHS AND TYPES AGAINST THE MDES TO ENSURE DATA COLLECTION RESPONSES DO NOT EXCEED THOSE OF THE MDES. SOME GENERAL ITEM LIMITS USED ARE AS FOLLOWS:

DATA ELEMENT FIELDS	MAXIMUM CHARACTERS PERMITTED	DATA TYPE	PROGRAMMER INSTRUCTIONS
ADDRESS AND EMAIL FIELDS	100	CHARACTER	
UNIT AND PHONE FIELDS	10	CHARACTER	
_OTH AND COMMENT FIELDS	255	CHARACTER	• Limit text to 255 characters
FIRST NAME AND LAST NAME	30	CHARACTER	• Limit text to 30 characters
ALL ID FIELDS	36	CHARACTER	
ZIP CODE	5	NUMERIC	
ZIP CODE LAST FOUR	4	NUMERIC	
CITY	50	CHARACTER	
DOB AND ALL OTHER DATE FIELDS (E.G., DT, DATE, ETC.)	10	NUMERIC CHARACTER	• DISPLAY AS MM/DD/YYYY • STORE AS YYYY-MM-DD • HARD EDITS: MM MUST EQUAL 01 TO 12 DD MUST EQUAL 01 TO 31 YYYY MUST BE BETWEEN 1900 AND CURRENT YEAR.
TIME VARIABLES	TWO-DIGIT HOUR AND TWO-DIGIT MINUTE, AM/PM DESIGNATION	NUMERIC	• HARD EDITS: HOURS MUST BE BETWEEN 00 AND 12; MINUTES MUST BE BETWEEN 00 AND 59

Instrument Guidelines for Participant and Respondent IDs:

PRENATALLY, THE **P_ID** IN THE MDES HEADER IS THAT OF THE PARTICIPANT (E.G. THE NON-PREGNANT WOMAN, PREGNANT WOMAN, OR THE FATHER).

POSTNATALLY, A RESPONDENT ID WILL BE USED IN ADDITION TO THE PARTICIPANT ID BECAUSE SOMEBODY OTHER THAN THE PARTICIPANT MAY BE COMPLETING THE INTERVIEW. FOR EXAMPLE, THE PARTICIPANT MAY BE THE CHILD AND THE RESPONDENT MAY BE THE MOTHER, FATHER, OR ANOTHER CAREGIVER.

THEREFORE, MDES VERSION 2.2 AND ALL FUTURE VERSIONS CONTAIN A **R_P_ID** (RESPONDENT PARTICIPANT ID) HEADER FIELD FOR EACH POST-BIRTH INSTRUMENT. THIS WILL ALLOW ROCs TO INDICATE WHETHER THE RESPONDENT IS SOMEBODY OTHER THAN THE PARTICIPANT ABOUT WHOM THE QUESTIONS ARE BEING ASKED.

A REMINDER:
ALL RESPONDENTS MUST BE CONSENTED AND HAVE RECORDS IN THE PERSON, PARTICIPANT, PARTICIPANT_CONSENT AND LINK_PERSON_PARTICIPANT TABLES, WHICH CAN BE PRELOADED INTO EACH INSTRUMENT. ADDITIONALLY, IN POST-BIRTH QUESTIONNAIRES WHERE THERE IS THE ABILITY TO LOOP THROUGH A SET OF QUESTIONS FOR MULTIPLE CHILDREN, IT IS IMPORTANT TO CAPTURE AND STORE THE CORRECT CHILD **P_ID** ALONG WITH THE LOOP INFORMATION. IN THE MDES VARIABLE LABEL/DEFINITION COLUMN, THIS IS INDICATED AS FOLLOWS: **EXTERNAL IDENTIFIER: PARTICIPANT ID FOR CHILD DETAIL.**

MOST RECENT PREGNANCY

(TIME_STAMP_MRP_ST).

MRP01000. I understand that this topic may be difficult to discuss. If at any time you find the questions too difficult to answer, please let me know and we can stop or skip to another item. Do you have any questions before we start?

INTERVIEWER INSTRUCTIONS
• ANSWER ANY QUESTIONS THE PARTICIPANT HAS.

MRP02000. First, I would like to ask you some questions about your most recent pregnancy [prior to the current pregnancy], including how the pregnancy ended.

INTERVIEWER INSTRUCTIONS
• IF PARTICIPANT IS PREGNANT, USE "prior to the current pregnancy".
• OTHERWISE, DO NOT READ "prior to the current pregnancy".

MRP03000/(PREG_MULTIPLE). Was your most recent pregnancy a <u>multiple pregnancy</u>, that is, were you pregnant with two or more babies?

Label	Code	Go To
YES	1	
NO	2	RECENT_LIVE_BORN
REFUSED	-1	RECENT_LIVE_BORN
DON'T KNOW	-2	RECENT_LIVE_BORN

SOURCE
National Survey of Family Growth, Cycle 6 Main Study (Female CAPI-Lite)

MRP04000/(NUM_CARRIED). How many babies did you carry during your most recent pregnancy, including any that were not born alive?

|___|___|
NUMBER OF BABIES

Label	Code	Go To
REFUSED	-1	
DON'T KNOW	-2	

SOURCE
Pregnancy Loss, Stillbirth, and Infant Death Instrument

MRP05000/(BORN_ALIVE). How many of your babies were <u>born alive</u>?

|___|___|
NUMBER OF LIVE BIRTHS

Label	Code	Go To
REFUSED	**-1**	
DON'T KNOW	**-2**	

INTERVIEWER INSTRUCTIONS
• IF THE PARTICIPANT REPORTS NONE, RECORD "00."

PROGRAMMER INSTRUCTIONS
• DISPLAY HARD EDIT IF **BORN_ALIVE** > **NUM_CARRIED.**
• IF **NUM_CARRIED** = **BORN_ALIVE**, GO TO **PRETERM_DELIVER**.
• OTHERWISE, GO TO **MRP06000**.

MRP06000. The next few questions I have will ask about what happened with each baby you carried during your most recent pregnancy. Sometimes in a pregnancy with more than one baby, each baby may have a different outcome. For example, one baby may be lost to a miscarriage, while another may be carried to term. We would like to know what happened to each of your babies in your recent pregnancy.

MRP07000/(NUM_STILLBORN). How many of your babies were <u>stillborn</u>, that is, lost at or after 20 weeks of pregnancy?

|___|___|
NUMBER OF BABIES

INTERVIEWER INSTRUCTIONS
• IF THE PARTICIPANT REPORTS NONE, RECORD "00."

Label	Code	Go To
REFUSED	**-1**	
DON'T KNOW	**-2**	

PROGRAMMER INSTRUCTIONS
• DISPLAY HARD EDIT IF **NUM_STILLBORN** > **NUM_CARRIED**.
• IF **BORN_ALIVE** + **NUM_STILLBORN** = **NUM_CARRIED**, GO TO **ECTOPIC_PREG**.
• OTHERWISE, GO TO **NUM_MISCARRIAGE**.

MRP08000/(NUM_MISCARRIAGE). During your most recent pregnancy, how many of your babies were lost due to a <u>miscarriage</u>, that is, an involuntary, unplanned pregnancy loss before 20 weeks of pregnancy?

|___|___|
NUMBER OF BABIES

Label	Code	Go To
REFUSED	-1	
DON'T KNOW	-2	

SOURCE

National Population Health Survey 1992, Mother's Survey

PROGRAMMER INSTRUCTIONS
- DISPLAY HARD EDIT IF **NUM_MISCARRIAGE** > **NUM_CARRIED**.
- IF **BORN_ALIVE + NUM_STILLBORN + NUM_MISCARRIAGE** = **NUM_CARRIED**, GO TO **ECTOPIC_PREG**.
- OTHERWISE, GO TO **INDUCED_ABORTION.**

MRP09000/(INDUCED_ABORTION). Did your most recent pregnancy involve an_induced abortion or elective reduction in the number of fetuses?

Label	Code	Go To
YES	1	
NO	2	ECTOPIC_PREG
REFUSED	-1	ECTOPIC_PREG
DON'T KNOW	-2	ECTOPIC_PREG

SOURCE

National Population Health Survey 1992, Mother's Survey

MRP10000/(NUM_ABORT). How many fetuses were aborted or reduced?

|___|___|
NUMBER OF FETUSES

Label	Code	Go To
REFUSED	-1	
DON'T KNOW	-2	

SOURCE

Pregnancy Loss, Stillbirth, and Infant Death Instrument

MRP11000/(ECTOPIC_PREG). Did your most recent pregnancy involve an <u>ectopic pregnancy</u>, in which an embryo implanted outside of the uterus? These are sometimes called <u>tubal pregnancies</u> because these pregnancies most often occur in the Fallopian tubes.

Label	Code	Go To
YES	1	
NO	2	
REFUSED	-1	
DON'T KNOW	-2	

SOURCE
National Population Health Survey 1992, Mother's Survey

PROGRAMMER INSTRUCTIONS
• IF **BORN_ALIVE** > 0, GO TO **PRETERM_DELIVER**.
• OTHERWISE, GO TO **MRP24000**.

MRP12000/(PRETERM_DELIVER). At the time of your {baby's/babies'} live birth, did you have a <u>preterm</u> delivery, that is, a delivery occurring <u>before 37 weeks</u> of pregnancy?

Label	Code	Go To
YES	1	
NO	2	
REFUSED	-1	
DON'T KNOW	-2	

SOURCE
National Survey of Family Growth, Cycle 6 Main Study (Female CAPI-Lite)

PROGRAMMER INSTRUCTIONS
• IF **BORN_ALIVE** = 1, DISPLAY, "baby's".
• IF **BORN_ALIVE** > 1, DISPLAY, "babies'".

MRP13000/(NUM_DIED). How many of your babies <u>died</u> after being born alive?

|___|___|
NUMBER OF BABIES

INTERVIEWER INSTRUCTIONS
• IF THE PARTICIPANT REPORTS NONE, RECORD "00."

Label	Code	Go To
REFUSED	-1	
DON'T KNOW	-2	

PROGRAMMER INSTRUCTIONS
- IF **NUM_DIED** = 0, -1, OR -2 GO TO **MRP24000**.
- OTHERWISE, GO TO **MULT_BEFORE_28**.

MRP14000/(MULT_BEFORE_28). Did your {baby/babies} die before 28 days <u>after birth</u>?

INTERVIEWER INSTRUCTIONS
- IF NEEDED, SAY "That is, the death of your {baby/babies} up to but not including 28 days from the moment of birth."

Label	Code	Go To
YES	1	
NO	2	MRP24000
REFUSED	-1	MRP24000
DON'T KNOW	-2	MRP24000

PROGRAMMER INSTRUCTIONS
- IF **NUM_DIED** = 1, DISPLAY, "baby".
- IF **NUM_DIED** > 1, DISPLAY, "babies".

MRP15000/(NUM_BEFORE_28). How many of your babies died before 28 days <u>after birth</u>?

|___|___|
NUMBER OF BABIES

INTERVIEWER INSTRUCTIONS
- IF THE PARTICIPANT REPORTS NONE, RECORD "00."

Label	Code	Go To
REFUSED	-1	MRP24000
DON'T KNOW	-2	MRP24000

PROGRAMMER INSTRUCTIONS
- GO TO **MRP24000**.

MRP16000/(RECENT_LIVE_BORN). Did your most recent pregnancy end with the delivery of a <u>live born baby</u>?

Label	Code	Go To
YES	1	

Label	Code	Go To
NO	2	STILLBIRTH_PREG
REFUSED	-1	STILLBIRTH_PREG
DON'T KNOW	-2	STILLBIRTH_PREG

MRP17000/(PRETERM_DELIVER_1). At the time of your baby's live birth, did you have a preterm delivery, that is, a delivery occurring <u>before 37 weeks</u> of pregnancy?

Label	Code	Go To
YES	1	
NO	2	
REFUSED	-1	
DON'T KNOW	-2	

MRP18000/(AFTER_BORN). Did your baby die after [he/she] was born?

Label	Code	Go To
YES	1	
NO	2	MRP24000
REFUSED	-1	MRP24000
DON'T KNOW	-2	MRP24000

MRP19000/(BEFORE_28). Did your baby die before 28 days<u> after birth?</u>

INTERVIEWER INSTRUCTIONS
• IF NEEDED SAY, "That is, the death of your baby up to but not including 28 days from the moment of birth."

Label	Code	Go To
YES	1	MRP24000
NO	2	MRP24000
REFUSED	-1	MRP24000
DON'T KNOW	-2	MRP24000

MRP20000/(STILLBIRTH_PREG). Did your most recent pregnancy end with a <u>stillbirth</u>, that is, a loss at or after 20 weeks of pregnancy?

Label	Code	Go To
YES	1	ECTOPIC_PREG1
NO	2	
REFUSED	-1	
DON'T KNOW	-2	

MRP21000/(MISCARRIAGE_PREG). Did your most recent pregnancy end with a <u>miscarriage</u>, that is, an involuntary, unplanned pregnancy loss <u>before 20 weeks</u> of pregnancy?

INTERVIEWER INSTRUCTIONS
• IF NEEDED SAY, "Was the loss due to an unplanned spontaneous abortion before 20 weeks of pregnancy?"

Label	Code	Go To
YES	1	ECTOPIC_PREG1
NO	2	
REFUSED	-1	
DON'T KNOW	-2	

MRP22000/(TERMINATION_PREG). Did your most recent pregnancy end with an <u>induced abortion</u> or voluntary termination?

Label	Code	Go To
YES	1	
NO	2	
REFUSED	-1	
DON'T KNOW	-2	

MRP23000/(ECTOPIC_PREG1). Did your most recent pregnancy involve an <u>ectopic pregnancy</u>, in which the embryo implanted outside of the uterus? These are sometimes called <u>tubal pregnancies</u> because these pregnancies most often occur in the Fallopian tubes.

Label	Code	Go To
YES	1	
NO	2	
REFUSED	-1	
DON'T KNOW	-2	

MRP24000. Now I would like to ask you some questions about your most recent pregnancy to help us understand the type of care you received, any problems you may have experienced, and any support you received after your loss.

MRP25000/(PRENATAL_PROV). Did you get <u>any prenatal care</u> from a doctor, nurse, or midwife during your most recent pregnancy?

Label	Code	Go To
YES	1	
NO	2	
REFUSED	-1	
DON'T KNOW	-2	

SOURCE
National Maternal and Infant Health Survey -2 1988, Mother's Survey

MRP26000/(RECENT_COMPLICATIONS). {I am going to read a list of pregnancy complications or conditions. For each complication or condition, please answer "yes" or "no" to let me know if you experienced it during your most recent pregnancy. If you aren't sure what the complication is, please let me know.}

During your most recent pregnancy, did you experience any of the following complications or conditions? You may select one or more.

INTERVIEWER INSTRUCTIONS
• IF USING SHOWCARDS, DO NOT READ RESPONSE OPTIONS AND REFER TO APPROPRIATE SHOWCARD.
• IF NOT USING SHOWCARDS, READ RESPONSE OPTIONS.
• PROBE, "Any others?"
• ONLY SELECT "SOME OTHER COMPLICATION" OR "NO COMPLICATIONS/CONDITIONS" IF VOLUNTEERED.
• SELECT ALL THAT APPLY.

Label	Code	Go To
HYPERTENSION (HIGH BLOOD PRESSURE)	1	
PRE-ECLAMPSIA (HIGH BLOOD PRESSURE AND EXCESS PROTEIN IN THE URINE AFTER 20 WEEKS OF PREGNANCY IN A WOMAN WHO PREVIOUSLY HAD NORMAL BLOOD PRESSURE)	2	
HELLP SYNDROME (HELLP IS "HEMOLYSIS, ELEVATED LIVER ENZYMES, LOW PLATELETS". THE SYNDROME INCLUDES THE BREAKDOWN OF RED	3	

Label	Code	Go To
BLOOD CELLS, ELEVATED LIVER ENZYMES, AND LOW PLATELET COUNT. IT OFTEN FOLLOWS A DIAGNOSIS OF HIGH BLOOD PRESSURE OR PRE-ECLAMPSIA)		
CERVICAL INCOMPETENCE(A CONDITION WHERE THE CERVIX IS TOO WEAK TO STAY CLOSED DURING A PREGNANCY AND BEGINS TO DILATE WITHOUT CONTRACTIONS BEFORE THE BABY IS READY TO BE BORN. IT IS OFTEN TREATED WITH CERCLAGE, THAT IS, STITCHING THE CERVIX CLOSED)	4	
PLACENTAL ABRUPTION (OCCURS WHEN THE PLACENTA SEPARATES FROM THE WALL OF THE UTERUS PRIOR TO THE BIRTH OF THE BABY)	5	
TRAUMA (SUCH AS A SERIOUS OR CRITICAL BODILY INJURY, WOUND, OR SHOCK)	6	
INFECTION (SUCH AS INFECTIONS FROM A BACTERIA OR VIRUS)	7	
UMBILICAL CORD PROBLEMS (SUCH AS A KNOT IN THE CORD, A LEAK IN THE CORD, OR IF THE CORD WRAPS AROUND THE BABY'S NECK)	8	
PREMATURE RUPTURE OF MEMBRANES (OCCURS WHEN THE SAC CONTAINING THE DEVELOPING BABY AND THE AMNIOTIC FLUID BURSTS OR DEVELOPS A HOLE PRIOR TO THE START OF LABOR, RESULTING IN THE LEAKAGE OF AMNIOTIC FLUID)	9	
PRETERM LABOR (OCCURS WHEN LABOR BEGINS	10	

Label	Code	Go To
BEFORE 37 COMPLETED WEEKS OF PREGNANCY)		
RHEUMATOLOGIC PROBLEMS (SUCH AS LUPUS AND OTHER SYSTEMIC AUTOIMMUNE DISEASES)	11	
DIAGNOSIS OF FETAL ANOMALIES OR CHROMOSOMAL ABNORMALITIES (SUCH AS WHEN THE BABY'S BODY PARTS OR ORGANS ARE NOT FORMED NORMALLY OR DO NOT FUNCTION)	12	
GESTATIONAL DIABETES (CONDITION OF HIGH BLOOD SUGAR DURING PREGNANCY AMONG WOMEN WITHOUT PREVIOUSLY DIAGNOSED DIABETES)	13	
SEVERE VOMITING (SUCH AS VOMITING THREE TO FOUR TIMES PER DAY. SOMETIMES CALLED "HYPEREMESIS" OR "HYPEREMESIS GRAVIDARUM")	14	
UTERINE BLOOD CLOTS (ALSO KNOWN AS "SUBCHORIONIC HEMATOMA")	15	
NO COMPLICATIONS/CONDITIONS	16	
SOME OTHER COMPLICATION	-5	
REFUSED	-1	
DON'T KNOW	-2	

PROGRAMMER INSTRUCTIONS
- IF **RECENT_COMPLICATIONS** = -5, OR ANY COMBINATION OF 1 THROUGH 15 AND -5, GO TO **RECENT_COMPLICATIONS_OTH**.
- IF **RECENT_COMPLICATIONS** = 16, -1 OR -2, DO NOT ALLOW ANY OTHER RESPONSES AND
  - o IF **TERMINATION_PREG** = 1, GO TO **RECEIVE_RESOURCES**.
  - o IF **TERMINATION_PREG** = 2, -1, OR -2, GO TO **DEATH_CAUSE**
- IF **RECENT_COMPLICATION**S = ANY COMBINATION OF 1 THROUGH 15, AND

MRP27000/(RECENT_COMPLICATIONS_OTH). What other complications did you experience during your recent pregnancy?

SPECIFY: _____

Label	Code	Go To
REFUSED	-1	
DON'T KNOW	-2	

PROGRAMMER INSTRUCTIONS
• IF **TERMINATION_PREG** = 1, GO TO **RECEIVE_RESOURCES**. • OTHERWISE, GO TO **DEATH_CAUSE**.

MRP28000/(DEATH_CAUSE). Do you know the cause of your {pregnancy loss/baby's death}? Do you know the cause of your {pregnancy loss/baby's death}?

Label	Code	Go To
YES	1	
NO	2	RECEIVE_RESOURCES
REFUSED	-1	RECEIVE_RESOURCES
DON'T KNOW	-2	RECEIVE_RESOURCES

PROGRAMMER INSTRUCTIONS

• IF **PREG_MULTIPLE** = 1 AND
    o **NUM_DIED** ≠ 0, -1 OR -2, DISPLAY "baby's death".
    o OTHERWISE, IF **NUM_DIED** = 0, -1, OR -2, DISPLAY "pregnacy loss".
• IF **PREG_MULTIPLE** = 2 AND
    o **AFTER_BORN** = 1, DISPLAY "baby's death"
    o **STILLBIRTH_PREG** = 1 OR **MISCARRIAGE_PREG** = 1, DISPLAY "pregnancy loss".

MRP29000/(DEATH_CAUSE_OTH). What was the cause?

SPECIFY: _____

Label	Code	Go To
REFUSED	-1	
DON'T KNOW	-2	

MRP30000/(RECEIVE_RESOURCES). After your most recent pregnancy, did you receive any support or draw on any resources that helped you with your {pregnancy loss/baby's death}, including from family, friends, health care providers, organizations, or other sources?

INTERVIEWER INSTRUCTIONS
• IF LOSS REPORTED DURING PREGNANCY VISIT 1 OR PREGNANCY VISIT 2 EVENT, USE "pregnancy loss" AS APPROPRIATE. • IF LOSS REPORTED DURING BIRTH EVENT, USE "baby's death" AS APPROPRIATE.

Label	Code	Go To
YES	**1**	
NO	**2**	**TIME_STAMP_MRP_ET**
REFUSED	**-1**	**TIME_STAMP_MRP_ET**
DON'T KNOW	**-2**	**TIME_STAMP_MRP_ET**

PROGRAMMER INSTRUCTIONS

• IF **PREG_MULTIPLE** = 1 AND
  o **NUM_DIED** ≠ 0, -1, OR -2, DISPLAY "baby's death".
  o OTHERWISE, IF **NUM_DIED** = 0, -1, OR -2, DISPLAY "pregnacy loss".
• IF **PREG_MULTIPLE** = 2 AND
  o **AFTER_BORN** = 1, DISPLAY "baby's death"
  o **STILLBIRTH_PREG** = 1 OR **MISCARRIAGE_PREG** = 1, DISPLAY "pregnancy loss".

MRP31000/(SUPPORT_HELPED). We would like to know what types of support or resources helped you after your recent loss. Please tell me if any of the following types of support or resources helped you.

INTERVIEWER INSTRUCTIONS
• IF USING SHOWCARDS, DO NOT READ RESPONSE OPTIONS AND REFER TO APPROPRIATE SHOWCARD. • IF NOT USING SHOWCARDS, READ RESPONSE OPTIONS. • PROBE, "Any others?" • ONLY SELECT "SOME OTHER TYPE OF SUPPORT OR RESOURCES" OR "NO TYPE OF SUPPORT OR RESOURCES" IF VOLUNTEERED. • SELECT ALL THAT APPLY.

Label	Code	Go To
EMOTIONAL SUPPORT FROM FAMILY OR FRIENDS	**1**	
IN-PERSON SUPPORT	**2**	

Label	Code	Go To
GROUP ON PREGNANCY LOSS AND INFANT DEATH		
WEB-BASED SUPPORT GROUP ON PREGNANCY LOSS AND INFANT DEATH	3	
BOOKS AND/OR MAGAZINES ON PREGNANCY LOSS AND INFANT DEATH	4	
INFORMATION FROM MEDICAL CARE PROVIDERS ON PREGNANCY LOSS AND INFANT DEATH	5	
MEDICAL TREATMENT	6	
MENTAL HEALTH COUNSELING	7	
PAID OR UNPAID LEAVE FROM YOUR JOB, INCLUDING MATERNITY LEAVE OR FAMILY AND MEDICAL LEAVE	8	
NO TYPE OF SUPPORT OR RESOURCES	9	
SOME OTHER TYPE OF SUPPORT OR RESOURCES	-5	
REFUSED	-1	
DON'T KNOW	-2	

SOURCE
Pregnancy Loss, Stillbirth, and Infant Death Instrument

PROGRAMMER INSTRUCTIONS
• IF **PREG_MULTIPLE** = 1 AND o **NUM_DIED** ≠ 0, -1 OR -2, DISPLAY "baby's death". o OTHERWISE, IF **NUM_DIED** = 0, -1, OR -2, DISPLAY "pregnacy loss". • IF **PREG_MULTIPLE** = 2 AND o **AFTER_BORN** = 1, DISPLAY "baby's death" o **STILLBIRTH_PREG** = 1 OR **MISCARRIAGE_PREG** = 1, DISPLAY "pregnancy loss". • IF **SUPPORT_HELPED** = -5, OR ANY COMBINATION OF 1 THROUGH 8 AND -5, GO TO **SUPPORT_OTH**. • IF **SUPPORT_HELPED** = 9, -1 OR -2, DO NOT ALLOW ANY OTHER RESPONSES AND GO TO **TIME_STAMP_MRP_ET.** • IF **SUPPORT_HELPED** = ANY COMBINATION OF 1 THROUGH 8, GO TO **TIME_STAMP_MRP_ET.**

MRP32000/(SUPPORT_OTH). What other types of support or resources helped you?

SPECIFY: _____

Label	Code	Go To
REFUSED	**-1**	
DON'T KNOW	**-2**	

PROGRAMMER INSTRUCTIONS
- IF **PREG_MULTIPLE** = 1 AND
  - **NUM_DIED** ≠ 0, -1 OR -2, DISPLAY "baby's death".
  - OTHERWISE, IF **NUM_DIED** = 0, -1, OR -2, DISPLAY "pregnacy loss".
- IF **PREG_MULTIPLE** = 2 AND
  - **AFTER_BORN** = 1, DISPLAY "baby's death"
  - **STILLBIRTH_PREG** = 1 OR **MISCARRIAGE_PREG** = 1, DISPLAY "pregnancy loss".

(TIME_STAMP_MRP_ET).

PROGRAMMER INSTRUCTIONS
- INSERT DATE/TIME STAMP

OBSTETRIC HISTORY

(TIME_STAMP_OH_ST).

OH01000. I have just a few more questions I would like to ask you. These questions are about your pregnancies prior to your most recent pregnancy.

OH02000/(NUM_PREG_PRIOR). How many times had you ever been pregnant <u>before your most recent pregnancy</u>, including any that may have ended in a live birth, miscarriage, stillbirth, induced abortion, or ectopic pregnancy?

|___|___|
NUMBER OF PRIOR PREGNANCIES

INTERVIEWER INSTRUCTIONS
• IF THE PARTICIPANT REPORTS NONE, RECORD "00."

Label	Code	Go To
REFUSED	**-1**	
DON'T KNOW	**-2**	

SOURCE
National Population Health Survey 1992, Mother's Survey

PROGRAMMER INSTRUCTIONS
• IF **NUM_PREG_PRIOR** = 0, GO TO **TIME_STAMP_OH_ET**.
• OTHERWISE, GO TO **NUM_PRIOR_MULT.**

OH03000/(NUM_PRIOR_MULT). How many of your prior pregnancies were <u>multiple pregnancies,</u> that is, you were pregnant with two or more babies?

|___|___|
NUMBER OF PRIOR MULTIPLE PREGNANCIES

INTERVIEWER INSTRUCTIONS
• IF THE PARTICIPANT REPORTS NONE, RECORD "00."

Label	Code	Go To
REFUSED	**-1**	
DON'T KNOW	**-2**	

SOURCE
National Survey of Family Growth, Cycle 6 Main Study (Female CAPI-Lite)

PROGRAMMER INSTRUCTIONS
• IF **NUM_PRIOR_MULT** = 0, GO TO **OH12000.**

PROGRAMMER INSTRUCTIONS
• OTHERWISE, GO TO **OH04000**.

OH04000. How many of these prior multiple pregnancies involved…

OH05000/(NUM_MULT_PRIOR_LIVE). The delivery of a <u>live born baby</u>?

|___|___|
NUMBER OF PRIOR LIVE BIRTH PREGNANCIES

INTERVIEWER INSTRUCTIONS
• IF THE PARTICIPANT REPORTS NONE, RECORD "00."

Label	Code	Go To
REFUSED	-1	
DON'T KNOW	-2	

SOURCE
National Population Health Survey 1992, Mother's Survey

OH06000/(NUM_MULT_PRIOR_PRETERM). A <u>preterm delivery</u>, or a delivery occurring <u>before 37 weeks</u> of pregnancy?

|___|___|
NUMBER OF TIMES

INTERVIEWER INSTRUCTIONS
• IF THE PARTICIPANT REPORTS NONE, RECORD "00."
• RE-READ INTRODUCTORY STATEMENT (How many involved…) AS NEEDED.

Label	Code	Go To
REFUSED	-1	
DON'T KNOW	-2	

SOURCE
National Survey of Family Growth, Cycle 6 Main Study (Female CAPI-Lite)

OH07000/(NUM_MULT_PRIOR_DEATH). The <u>death of a baby</u> before 28 days <u>after birth?</u>
|___|___|
NUMBER OF TIMES

INTERVIEWER INSTRUCTIONS
• IF NEEDED, SAY: "That is, the death of your baby up to but not including 28 days from the moment of birth."
• IF THE PARTICIPANT REPORTS NONE, RECORD "00."
• RE-READ INTRODUCTORY STATEMENT (How many involved…) AS NEEDED.

Label	Code	Go To
REFUSED	-1	

Label	Code	Go To
DON'T KNOW	**-2**	

OH08000/(NUM_MULT_PRIOR_MISCARRIAGE). A <u>miscarriage</u>, that is, an involuntary, unplanned pregnancy loss <u>before 20 weeks</u> of pregnancy?

|___|___|
NUMBER OF PRIOR MISCARRIAGE PREGNANCIES

INTERVIEWER INSTRUCTIONS
• IF THE PARTICIPANT REPORTS NONE, RECORD "00."
• RE-READ INTRODUCTORY STATEMENT (How many involved…) AS NEEDED.

Label	Code	Go To
REFUSED	**-1**	
DON'T KNOW	**-2**	

OH09000/(NUM_MULT_PRIOR_STILLBIRTH). A <u>stillbirth</u> at 20 weeks of pregnancy or later?

|___|___|
NUMBER OF PREGNANCIES

INTERVIEWER INSTRUCTIONS
• IF THE PARTICIPANT REPORTS NONE, RECORD "00."
• RE-READ INTRODUCTORY STATEMENT (How many involved…) AS NEEDED.

Label	Code	Go To
REFUSED	**-1**	
DON'T KNOW	**-2**	

OH10000/(NUM_MULT_PRIOR_ABORTION). An <u>induced abortion</u> or voluntary termination?

|___|___|
NUMBER OF PRIOR ABORTED PREGNANCIES

INTERVIEWER INSTRUCTIONS
• IF THE PARTICIPANT REPORTS NONE, RECORD "00."
• RE-READ INTRODUCTORY STATEMENT (How many involved…) AS NEEDED.

Label	Code	Go To
REFUSED	**-1**	
DON'T KNOW	**-2**	

OH11000/(NUM_MULT_PRIOR_ECTOPIC). An <u>ectopic pregnancy</u>, in which the embryo implanted outside of the uterus? These are sometimes called <u>tubal pregnancies</u> because these pregnancies most often occur in the Fallopian tubes.

|___|___|
NUMBER OF PRIOR ECTOPIC PREGNANCIES

INTERVIEWER INSTRUCTIONS
- IF THE PARTICIPANT REPORTS NONE, RECORD "00."
- RE-READ INTRODUCTORY STATEMENT (How many involved…) AS NEEDED.

Label	Code	Go To
REFUSED	**-1**	
DON'T KNOW	**-2**	

PROGRAMMER INSTRUCTIONS
- IF **NUM_PRIOR_MULT** = **NUM_PREG_PRIOR**, GO TO **TIME_STAMP_OH_ET**.
- OTHERWISE, GO TO **OH12000**.

OH12000. Now I would like to ask you about your pregnancies prior to your most recent pregnancy in which you were pregnant with just one baby.

OH13000. How many of these prior pregnancies {with one baby} ended with:

PROGRAMMER INSTRUCTIONS
- DISPLAY "with one baby" IF **NUM_PRIOR_MULT** ≠ 0.

OH14000/(NUM_ONE_PRIOR_LIVE). The delivery of a <u>live born baby</u>?

|___|___|
NUMBER OF TIMES

INTERVIEWER INSTRUCTIONS
- IF THE PARTICIPANT REPORTS NONE, RECORD "00."

Label	Code	Go To
REFUSED	**-1**	
DON'T KNOW	**-2**	

National Population Health Survey 1992, Mother's Survey

PROGRAMMER INSTRUCTIONS
- IF **NUM_ONE_PRIOR_LIVE** = 0, GO TO **NUM_ONE_PRIOR_MISCARRIAGE**.
- OTHERWISE, GO TO **NUM_ONE_PRIOR_PRETERM.**

OH15000/(NUM_ONE_PRIOR_PRETERM). A <u>preterm delivery</u>, or a delivery occurring <u>before 37 weeks</u> of pregnancy?

|___|___|
NUMBER OF TMES

INTERVIEWER INSTRUCTIONS
- IF THE PARTICIPANT REPORTS NONE, RECORD "00."
- RE-READ INTRODUCTORY STATEMENT (How many ended in…) AS NEEDED.

Label	Code	Go To
REFUSED	-1	
DON'T KNOW	-2	

National Survey of Family Growth, Cycle 6 Main Study (Female CAPI-Lite)

OH16000/(NUM_ONE_PRIOR_BEFORE_28). The <u>death of your baby</u> before 28 days <u>after birth?</u>

|___|___|
NUMBER OF TIMES

INTERVIEWER INSTRUCTIONS
- IF THE PARTICIPANT REPORTS NONE, RECORD "00."
- IF NEEDED SAY, "That is, the death of your baby up to but not including 28 days from the moment of birth."
- RE-READ INTRODUCTORY STATEMENT (How many ended in…) AS NEEDED.

Label	Code	Go To
REFUSED	-1	
DON'T KNOW	-2	

Pregnancy Loss, Stillbirth, and Infant Death Instrument

OH17000/(NUM_ONE_PRIOR_MISCARRIAGE). A <u>miscarriage</u>, that is, an involuntary, unplanned pregnancy loss <u>before 20 weeks</u> of pregnancy?

|___|___|
NUMBER OF TIMES

Label	Code	Go To
REFUSED	-1	
DON'T KNOW	-2	

OH18000/(NUM_ONE_PRIOR_STILLBIRTH). A <u>stillbirth</u> at 20 weeks of pregnancy or later?

|___|___|
NUMBER OF TIMES

INTERVIEWER INSTRUCTIONS
• IF THE PARTICIPANT REPORTS NONE, RECORD "00."
• RE-READ INTRODUCTORY STATEMENT (How many ended in…) AS NEEDED.

Label	Code	Go To
REFUSED	-1	
DON'T KNOW	-2	

OH19000/(NUM_ONE_PRIOR_ABORTION). An <u>induced abortion</u> or voluntary termination?

|___|___|
NUMBER OF TIMES

INTERVIEWER INSTRUCTIONS
• IF THE PARTICIPANT REPORTS NONE, RECORD "00."
• RE-READ INTRODUCTORY STATEMENT (How many ended in…) AS NEEDED.

Label	Code	Go To
REFUSED	-1	
DON'T KNOW	-2	

OH20000/(NUM_ONE_PRIOR_ECTOPIC). An <u>ectopic pregnancy</u>, in which the embryo implanted outside of the uterus? These are sometimes called <u>tubal pregnancies</u> because these pregnancies most often occur in the Fallopian tubes.

|___|___|
NUMBER OF TIMES

INTERVIEWER INSTRUCTIONS

- IF THE PARTICIPANT REPORTS NONE, RECORD "00."
- RE-READ INTRODUCTORY STATEMENT (How many ended in…) AS NEEDED.

Label	Code	Go To
REFUSED	**-1**	
DON'T KNOW	**-2**	

PROGRAMMER INSTRUCTIONS

- CREATE DERIVED VARIABLE, **NUM_PRIOR_ONE_CALC**, WHERE **NUM_PRIOR_ONE_CALC** = SUM OF **NUM_ONE_PRIOR_LIVE** + **NUM_ONE_PRIOR_MISCARRIAGE** + **NUM_ONE_PRIOR_STILLBIRTH** + **NUM_ONE_PRIOR_ABORTION** + **NUM_ONE_PRIOR_ECTOPIC**; THEN SET **NUM_PREG_PRIOR** = **NUM_PRIOR_ONE_CALC** + **NUM_PRIOR_MULT.**

(TIME_STAMP_OH_ET).

PROGRAMMER INSTRUCTIONS

- INSERT DATE/TIME STAMP

RECORDS RELEASE REQUESTS

(TIME_STAMP_RRR_ST).

PROGRAMMER INSTRUCTIONS
• INSERT DATE/TIME STAMP

RRR01000. Thank you for answering our questions about this difficult topic. We appreciate your participation. To better understand your loss, we would like to review your medical record related to your most recent pregnancy. Information from your medical record will only be seen by members of the NCS study team. Your doctors, hospitals, and other medical care providers can tell us more about your pregnancy and the care you and your baby received. What your medical care providers can tell us is also very important to understanding your loss.

{We would like to send you two copies of a Medical Record Release form in the mail. If you have questions after reading the form, please contact us at the number we will include on the form. If you agree to let us access the medical records, you will complete and sign the form, and mail it back to us. We will provide a pre-addressed stamped envelope for this purpose. The second copy of the form will be yours to keep.}

PROGRAMMER INSTRUCTIONS
• IF MODE = CATI, DISPLAY BRACKETED TEXT AND THEN GO TO **MAILING_ADDRESS_VARIABLES**.
• OTHERWISE, IF MODE = CAPI, GO TO **MED_RECORD_LOSS**.

RRR02000/(MAILING_ADDRESS_VARIABLES). What is your mailing address?

INTERVIEWER INSTRUCTIONS
• PROBE AND ENTER AS MUCH INFORMATION AS PARTICIPANT KNOWS.

Label	Code	Go To
REFUSED	**-1**	**RRR12000**
DON'T KNOW	**-2**	**RRR12000**

SOURCE
Pregnancy Loss, Stillbirth, and Infant Death Instrument

(MAIL_ADDRESS_1) _____
ADDRESS 1 - STREET/PO BOX

(MAIL_ADDRESS_2)

_____
ADDRESS 2

(MAIL_UNIT) _____
UNIT

(MAIL_CITY) _____
CITY

(MAIL_STATE) |___|___|
STATE

(MAIL_ZIP) |___|___|___|___|___|
ZIP CODE

(MAIL_ZIP4) |___|___|___|___|
ZIP+4

RRR03000/(MED_RECORD_LOSS). May we {have your permission to access your medical records to learn more about the loss/send you the Medical Record Release form to review}?

Label	Code	Go To
YES {ALLOWS MAILING}	1	
NO {SAID DOES NOT WANT RELEASE MAILED TO HER}	2	
REFUSED	-1	
DON'T KNOW	-2	

PROGRAMMER INSTRUCTIONS
• IF MODE = CAPI, DISPLAY "have your permission to access your medical records to learn more about the loss."   • IF MODE = CATI, DISPLAY "send you the Medical Record Release form to review" AND BRACKETED TEXT FOR RESPONSE CODES.   • IF MODE = CAPI AND **MED_RECORD_LOSS** = 1, GO TO **RRR04000**.   • IF MODE = CATI AND **MED_RECORD_LOSS** = 1, GO TO **REVIEW_RELEASE**.   • OTHERWISE, GO TO PROGRAMMER INSTRUCTIONS FOLLOWING **SIGN_RELEASE**.

RRR04000. Please read and complete the Medical Record Release Form and let me know if you have any questions. All of the information we obtain will be kept strictly confidential.

INTERVIEWER INSTRUCTIONS
• PROVIDE PARTICIPANT WITH TWO COPIES OF THE MEDICAL RECORD RELEASE FORM.   • ANSWER ANY QUESTIONS THE PARTICIPANT HAS.   • THE PARTICIPANT SHOULD SIGN ONE COPY FOR THE INTERVIEWER, AND SHE SHOULD BE GIVEN THE OTHER COPY TO KEEP.

RRR05000/(SIGN_RELEASE). DID PARTICIPANT SIGN THE MEDICAL RECORD RELEASE?

Label	Code	Go To
YES	1	
NO	2	

PROGRAMMER INSTRUCTIONS
- IF **NUM_STILLBORN** > 0 AND/OR **NUM_DIED** > 0, AND **STILLBIRTH_PREG** = 1, OR **AFTER_BORN** = 1, GO TO **RRR07000**.   - OTHERWISE, GO TO **RRR12000**.

RRR06000/(REVIEW_RELEASE). DID PARTICIPANT AGREE TO REVIEW THE MEDICAL RECORD RELEASE?

Label	Code	Go To
YES	1	
NO	2	

PROGRAMMER INSTRUCTIONS
- IF **NUM_STILLBORN** > 0 AND/OR **NUM_DIED** > 0, AND **STILLBIRTH_PREG** = 1, OR **AFTER_BORN** = 1, GO TO **RRR07000**.   - OTHERWISE, GO TO **RRR12000**.

RRR07000. Your {baby's/babies'} death certificate{s} can give us important information about the {cause of/circumstances of your {baby's/babies'}} death. All of the information we obtain will be kept strictly confidential and will only be seen by members of the NCS study team. {We will send you 2 copies of a Death Certificate Release form in the mail {per child}. Please review and complete the form{s}. If you have questions after you read the Death Certificate Release form, please contact us at the number we will include on the form. Once you have completed and signed the release form, please mail it back to us, using the same envelope as you will use for sending us the Medical Records Release form. The second copy of the form will be yours to keep.}

PROGRAMMER INSTRUCTIONS
- IF MODE = CAPI, DISPLAY "cause of."   - IF MODE = CATI, DISPLAY "circumstances of your {baby's/babies'}" AND BRACKETED PARAGRAPH THAT BEGINS "We will send you 2 copies…".   - IF **PREG_MULTIPLE** = 1, DISPLAY "per child".   - IF **PREG_MULTIPLE** = 1 AND SUM OF **NUM_STILLBORN** + **NUM_DIED** = 1, DISPLAY "baby's", "certificate" AND "form".   - OTHERWISE, IF **PREG_MULTIPLE** = 1 AND SUM OF **NUM_STILLBORN** + **NUM_DIED** > 1, DISPLAY "babies", "certificates" AND "forms".

RRR08000/(DEATH_CERT). May we {also} {have your permission to access your {baby's/babies'} death certificate{s}/send you the Death Certificate Release form to review}?

Label	Code	Go To
YES{, ALLOWS MAILING}	1	
NO{, SAID DOES NOT WANT RELEASE MAILED TO HER}	2	
REFUSED	-1	
DON'T KNOW	-2	

PROGRAMMER INSTRUCTIONS
- IF **MED_RECORD_LOSS** = 1, DISPLAY, "also."
- IF MODE = CAPI, DISPLAY "have your permission to access your {baby's/babies'} death certificate{s}."
- IF MODE = CATI, DISPLAY "send you the Death Certificate Release form to review" AND BRACKETED TEXT FOR RESPONSE CODES.
- IF SUM OF **NUM_STILLBORN** + **NUM_DIED** = 1, DISPLAY "baby's and "certificate".
- OTHERWISE, IF SUM OF **NUM_STILLBORN** + **NUM_DIED** > 1, DISPLAY "babies" and "certificates".
- IF MODE = CAPI AND **DEATH_CERT** = 1, GO TO **RRR09000**.
- IF MODE = CATI AND **DEATH_CERT** = 1, GO TO **REVIEW_DEATH_CERT**.
- OTHERWISE, GO TO **RRR12000**.

RRR09000. Please read and complete the Death Certificate Record Release Form and let me know if you have any questions.

INTERVIEWER INSTRUCTIONS
- PROVIDE PARTICIPANT WITH TWO COPIES OF THE DEATH CERTIFICATE RELEASE FORM FOR EACH CHILD.
- OBTAIN RELEASE FORM WHERE NUMBER OF RELEASE FORMS = SUM OF **NUM_STILLBORN** + **NUM_DIED**.
- ANSWER ANY QUESTIONS THE PARTICIPANT HAS.
- HAVE THE PARTICIPANT SIGN ONE COPY OF THE FORM, AND GIVE HER THE OTHER COPY TO KEEP.

RRR10000/(SIGN_DEATH_CERT). DID PARTICIPANT SIGN THE DEATH CERTIFICATE RELEASE{S}?

Label	Code	Go To
YES	**1**	
NO	**2**	

PROGRAMMER INSTRUCTIONS
- IF SUM OF **NUM_STILLBORN** + **NUM_DIED** = 1, DISPLAY "release".
- OTHERWISE, IF SUM OF **NUM_STILLBORN** + **NUM_DIED** > 1, DISPLAY "releases".

RRR11000/(REVIEW_DEATH_CERT). DID PARTICIPANT AGREE TO REVIEW THE DEATH CERTIFICATE RELEASE{S}?

Label	Code	Go To
YES	**1**	
NO	**2**	

PROGRAMMER INSTRUCTIONS
- IF SUM OF **NUM_STILLBORN** + **NUM_DIED** = 1, DISPLAY "release".
- OTHERWISE, IF SUM OF **NUM_STILLBORN** + **NUM_DIED** > 1, DISPLAY

"releases".

RRR12000. Those are all the questions I have. I'd like to thank you for your help in answering our questions. Your participation is very important to the National Children's Study.

(TIME_STAMP_RRR_ET).

PROGRAMMER INSTRUCTIONS
- INSERT DATE/TIME STAMP